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Parental involvement network for parents of disabled children

Notes from the Huntingdon network meeting

Date: 8 October 2013 **Time:** 10am – 2pm

Venue: Medway Centre, Huntingdon

Number of parents and carers: 12

Professionals joining at 11am: 13

Facilitator: Lenja Bell, pinpoint

This was the 15th parental involvement network meeting for Huntingdon.

Workshop ground rules

The workshop ground rules were put up as a reminder for participants at the beginning of the meeting.

- Everyone is valued, we respect the views of others
- Everyone will have the chance to speak, be heard and to hear the person speaking
 - No side conversations
 - No talking over others
- There are not wrong answers or silly questions
- No jargon please
- We respect confidentiality
- Anything else?
- Mobile phone on 'silent' please

Updates

Pinpoint gave updates from previous network meetings. These are outlined in the document: *Parental involvement network for parents of disabled*

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children: feedback for October 2013 network meetings. Additional updates were:

- pinpoint asked parents to feedback on continence services so more information can be provided for parents on the pinpoint website. pinpoint will like to hear top tips from parents and what questions they would like answered.
- pinpoint is running three Talk about Transitions events in early November. The focus is 'independent living'.
- pinpoint is running an Empowering Parents course with Home-Start for parent of children with additional needs 5 years or younger. A course is currently running in March and the next one will be in Cambridge in November. More will be scheduled in the new year.
- The parent well-being and support group that runs in Cambridge once per month on a Monday morning has had its funding extended and will now run through March 2014. Each session has a well-being topic and speaker.

Hot topic: changing schools (transitions)

Parents only session

Cambridgeshire County Council is reviewing its services around school transitions, from early years to adult services. A Transitions Development Manager Anne Richardson is leading the process and is keen to capture parents' views regarding their experiences and what type of support they would like. Parents were asked to look at different stages of transitions:

Early years to primary

Primary to secondary

Other – mainstream to special school, special school to mainstream school, from out of area, from home-schooling, etc.

For each of the areas, parents were asked to feedback on the following questions:

What worked well?

What didn't work?

What was missing?

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What would you like?

Parents answered the questions individually and put their answers up on the sticky wall. We then discussed the answers as a group and added more comments. Parents' comments are listed below. Comments in italics were made by service providers and commissioners during the second part of the meeting when we discussed parents' comments with them. A Burning Issues area was also created to capture more general concerns.

Early Years to Primary

What worked well?

- TA meeting my son in Pre-School before starting primary.
- Fantastic support from visual impairment service - Gabriel started school with statement. We all knew what we were doing.
- Social story with photos of teacher/classes/toilet.
- Being able to tell other parents of son's autism.
- Communication book which details positive and negative.

What didn't work?

- Difficult to have discussion – no flexibility of options.
- Delay in support due to delay in statement, knock on effect on child's social skills – held back at school.
- School not ready to support child full-time.
- Transition between years, exclusion as result of TA change and less support.
- Schools do not always take notice of information passed on (from parents or pre-school).
- Schools slow in adapting to child's needs.
- Statement delay and school did not want him for full hours.
- We started looking after our foster child at the age of nearly five. The school he was at was fantastic for him, but the next one was a disaster, only attended one hour per day.
- Staff need to be trained to work with a child with additional needs.
- Expectations of child is too high.

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What was missing?

- No comments made.

What would you like?

- Honest feedback from school - good and bad.
- Parents not believed – parents are the experts
- Child at home is different. (behaviour)
- Social needs just as important.
- School take more notice of social needs. (e.g. provisions for play-time)
- Willingness to discuss flexible options.

Primary to secondary

General comment: Communication book is good with positive and negative things.

What worked well?

- Pre-transition meetings at secondary school with current (primary) TA.
- Very good communication from school during first week (Cabin in Comberton) – daily emails and answered concerns.

What didn't work?

- Homework
- Did not anticipate how much transition would affect my son, need support for parents.
- Transport issues.

What was missing?

- Need information on transport policy.
- Safety of our boys travelling to school if outside our area. (Two comments made.)
- *All transport staff should be trained*
- How to help our boy during the change of school, need support for parents.

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- Finding the right school to meet our child's needs, advice and help needed.
- Finding best option for your child.

What would you like?

- Knowing what options in terms of schools at secondary level are available for an autistic child, feels too secret.
- Individual advice for parents.

Mainstream to Special school

What did not work?

- Being left part time (half day) for too long (too slow of a transition) – tough on siblings.

What would you like?

- Knowing all the options that are available, information about schools.
- How do we know to look for the name of the school?
- *Schools will need to provide information on services – in Code of Practice.*
- *Contact FIS for help.*

From out of area

- Statement not recognized

From home schooled

- Also very difficult

General comments

- PPS can be really helpful re: exclusions
- (Need) more information on schools with help in finding a school

Burning Issues

- CAMH – problems accessing services
- Part time hours e.g. exclusion.
- Statement amendments and finalizing – long delays.

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- Specialist TA training needed to meet the needs of the child.
- Open and honest feedback from school, good and bad.

Feeding back to service providers and commissioners

Commissioners and service providers joined the meeting at 11am. After introductions, going over the ground rules, and a short introduction from Anne Richardson, we discussed parents' feedback from the earlier session. Responses and comments from professionals are written in italics in the above section.

The overarching themes from the discussion were:

- The need for the transition process to start early
- The value of good communication between settings
- The need for staff to be trained to meet the needs of pupils coming into the setting
- The need for support for parents in the transition process as well as the pupil
- Help for parents in identifying the right school for their child
- The need for good quality communication between school and parents – open, honest and timely
- The importance of consideration of the social as well as academic needs of the child
- Difficulties with the statementing process
- Difficulties where children were not in school

Group work

Anne then asked the parents to work in groups with service providers to review two items:

- An A3 page outlining the transitions process from early years to primary school with specific points of information on childcare / early learning, health care, starting school and co-ordinated support for you and your family.
- A draft website page with information about starting school.

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Anne wanted to find out if the information is useful to parents and if the layout is clear. Scribes in each group noted parent feedback which Anne collected and will use to develop the work further.

The group work ran over lunch, parents and service providers continued to talk and work together over sandwiches.

Evaluation

We asked parents and service providers to feedback on the meetings by answering a few questions on a flip chart. This was voluntary so unfortunately feedback was not always gathered. Comments from professionals are in italics. See feedback below:

Liked this

No comments made

Didn't like this

No comments made

More of this

No comments made

Anything else?

No comments made

Next meeting

The next meeting will be held on 4th March 2013 from 10am – 2pm at the Youth Hall, the Bargroves, Cromwell Road, St Neots PE19 2EY.

pinpoint actions

In response to issues raised at this meeting, we will:

1. Summarise and report findings to the Disabled Children's Action Group and SEND Project Board, and other groups that pinpoint is represented on.
2. Add the network meeting notes and summary report to the pinpoint website. Share the link in our weekly update.
3. Discuss key issues arising from the district network meetings at the county Partners in Commissioning (SEND) Group meeting in November 2013.